# Partnership for Kids:
# 2006 Statewide CASA Conference

October 13-14, Williamsburg, VA

# Effective Advocacy for Children with Disabilities

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# FACTS ABOUT CHILDREN WITH DISABILITIES

1. Experience all forms of abuse and neglect more often than other children.
2. More likely to experience multiple incidents of abuse from multiple perpetrators over a longer period of time.
3. Abuse and neglect can CAUSE disabilities.
4. Not fully protected by systems.
5. Deserve to live up to their full potential.

# GUIDING PRINCIPLES

## ALL children have the right to be . . . .

- Treated fairly, with dignity
- Protected from victimization
- Protected from re-victimization by systems

## ALL professionals have the responsibility to . . . .

- Be aware of disability issues
- Respect individual differences
- Consider needs when developing strategies
- Work towards reducing barriers

# DEFINITION OF DEVELOPMENTAL DISABILITIES

**Developmental disabilities are:**

- **Severe**
- **Life-long**
- **Attributable to mental and/or physical impairments**
- **Manifested before age 22**
- **Result in substantial limitations in 3+ major life activities:**
  - **Capacity for independent living**
  - **Economic self-sufficiency**
  - **Learning**
  - **Mobility**
  - **Receptive & expressive language**
  - **Self-care**
  - **Self-direction**

Developmental Disabilities Act of 2000 (Public Law 106-402)

# Abuse and neglect of children with disabilities is "a critical public health issue that must be addressed."

American Academy of Pediatrics, 2001

# INCIDENCE OF MALTREATMENT

## National Study

**Children without disabilities**

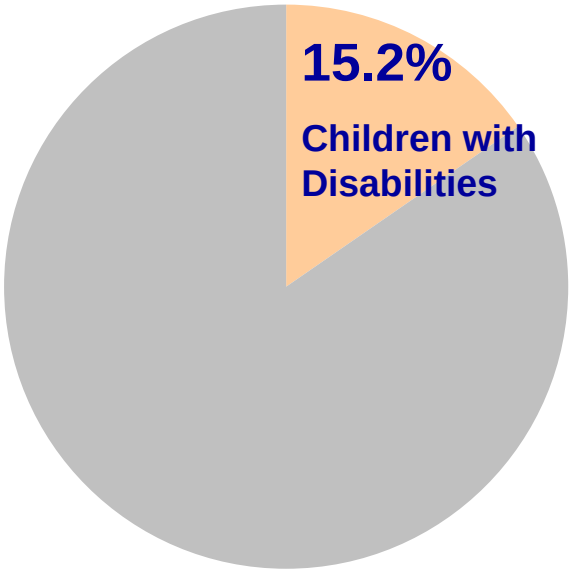
**Children with disabilities**

1.7 times greater maltreatment

# CHILD MALTREATMENT INCIDENCE
# Sullivan and Knutson Study (2000)

- Rate of abuse and neglect 3.4 times higher
- Victims were younger
- Behavior disorder highest prevalence
- Children with orthopedic, communication disabilities abused at younger ages
- Abuse and neglect occurred multiple times in multiple ways
- Increased risk of neglect

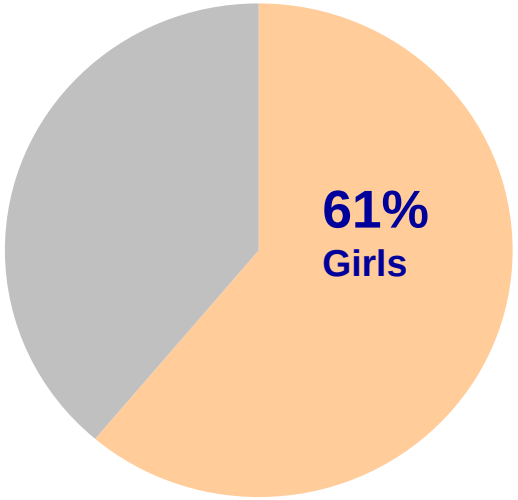
# SEXUAL ABUSE INCIDENCE

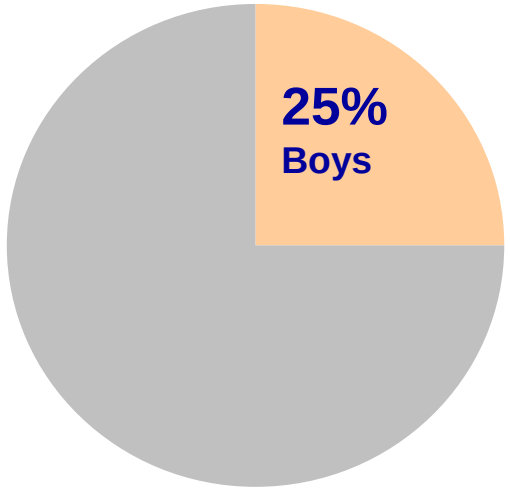



Children Experiencing Sexual Abuse

(Crosse, Kaye, & Ratnofsky, 1993)

# SEXUAL ABUSE OF CHILDREN WITH DISABILITIES BEFORE AGE 18




(McArthy and Thompson, 1997)

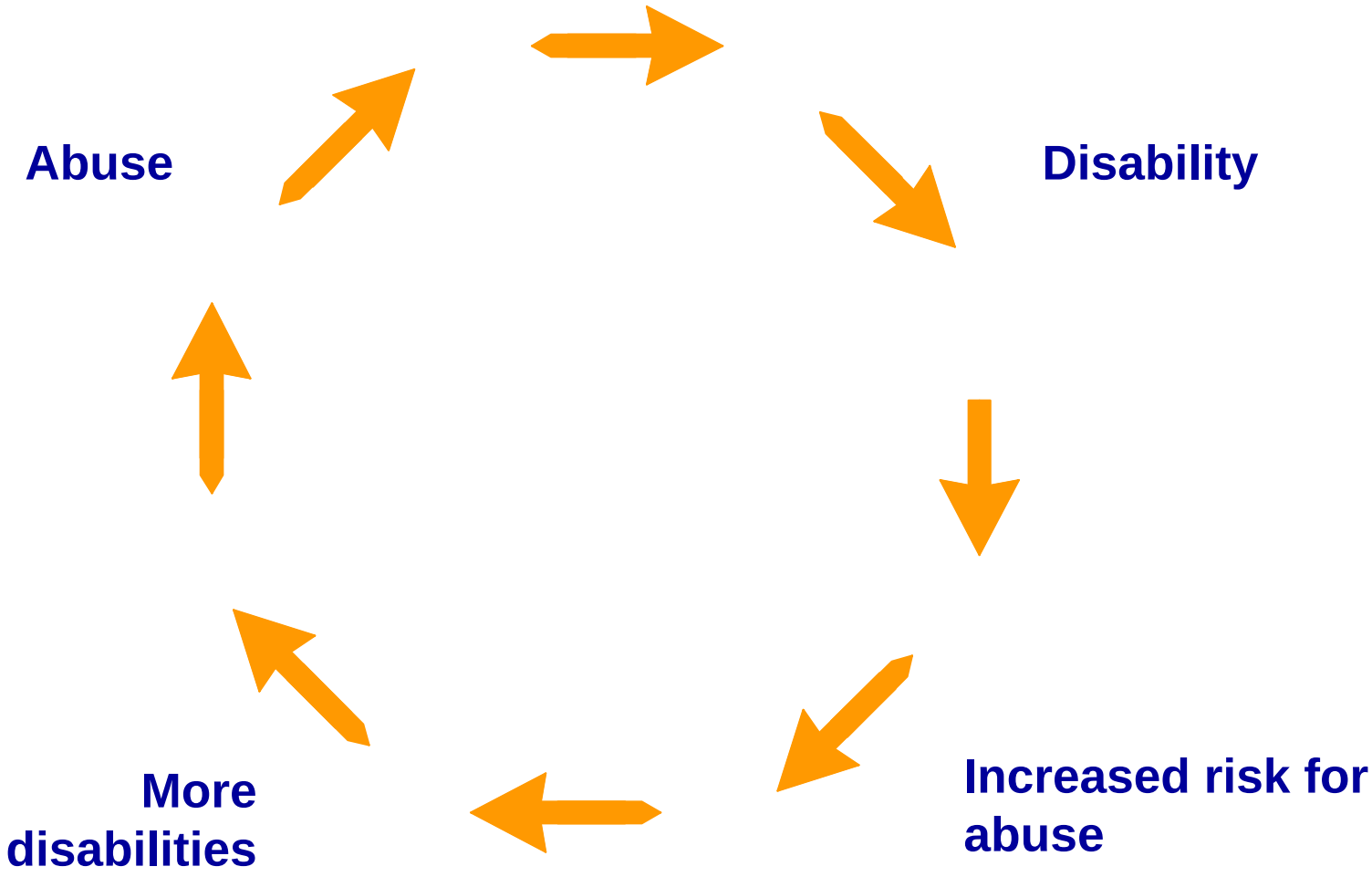
**Slide A-8**

# DEAF CHILDREN SEXUALLY ABUSED

- 54% Boys
- 50% Girls
- 50-75% Children in residential schools

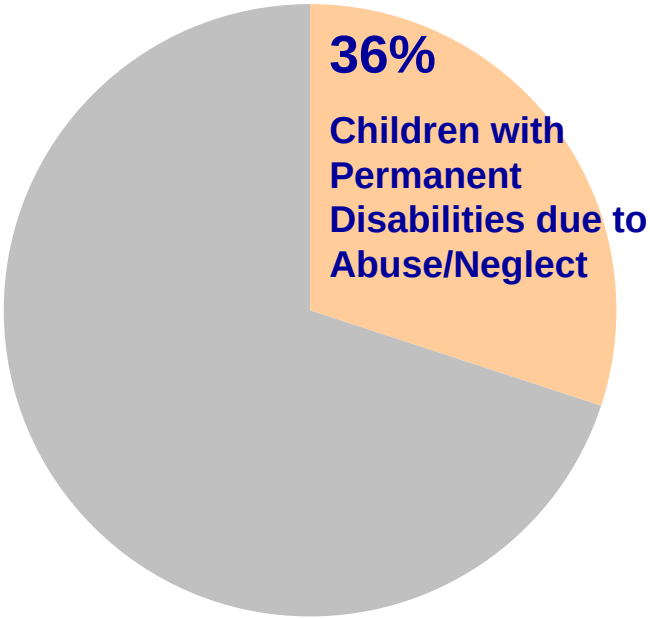
(Sullivan, Vernon, & Scanlan, 1987)

# RELATIONSHIP BETWEEN ABUSE AND DISABILITY



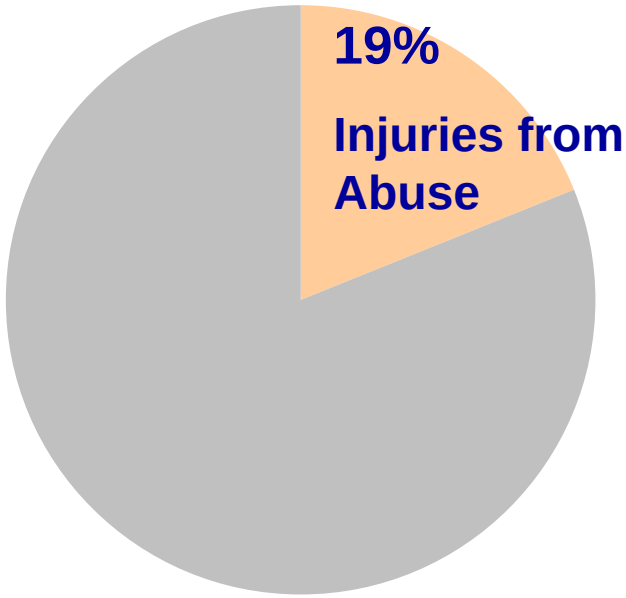

Sobsey, 1994

# KNOWN CHILD MALTREATMENT CASES




Crosse, Kaye, & Ratnofsky, 1993

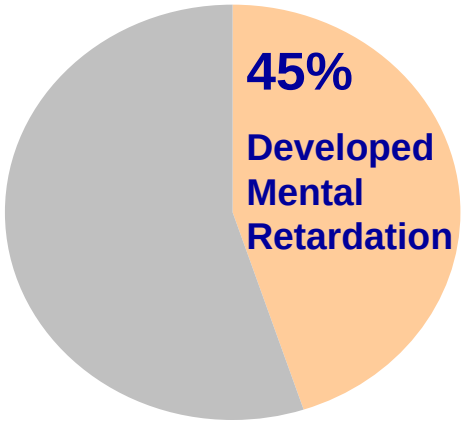
# CHILDREN UNDER AGE 6 HOSPITALIZED FOR BRAIN INJURY



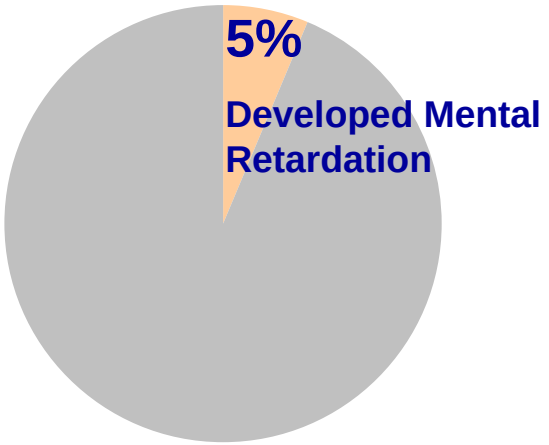

197 Serious Brain Injury Cases

Reece & Sege, 2000

## CHILDREN SURVIVING BRAIN INJURY DUE TO VIOLENCE




## CHILDREN SURVIVING BRAIN INJURY DUE TO ACCIDENTS



# CONSEQUENCES OF MALTREATMENT FOR CHILDREN WITH DISABILITIES

- Physical injuries
- Sexually transmitted diseases
- Pregnancy
- Emotional distress
- Social withdrawal
- Impaired ability to trust
- Learning difficulties
- PTSD
- Maltreatment-related disabilities
- Re-victimization
- More likely to perpetrate abuse

(National Organization for Victim Assistance, 2002)

# CASCADE OF INJUSTICES


Oregon Institute on Disability and Development, 1998

# COMMON CASE CHARACTERISTICS

- Multiple forms of maltreatment
- Multiple perpetrators
- Maltreatment of long duration
- Inadequate or inappropriate healthcare
- Multiple contacts with professionals who
  - Fail to recognize or respond
  - Ignore, misunderstand, or misinterpret signs
- Inappropriate use or misuse of treatments
- Misleading caregiver behaviors and statements
- Use disability to explain away
- Being blamed for injuries
- Empathy for caregivers
- Rejection of reports

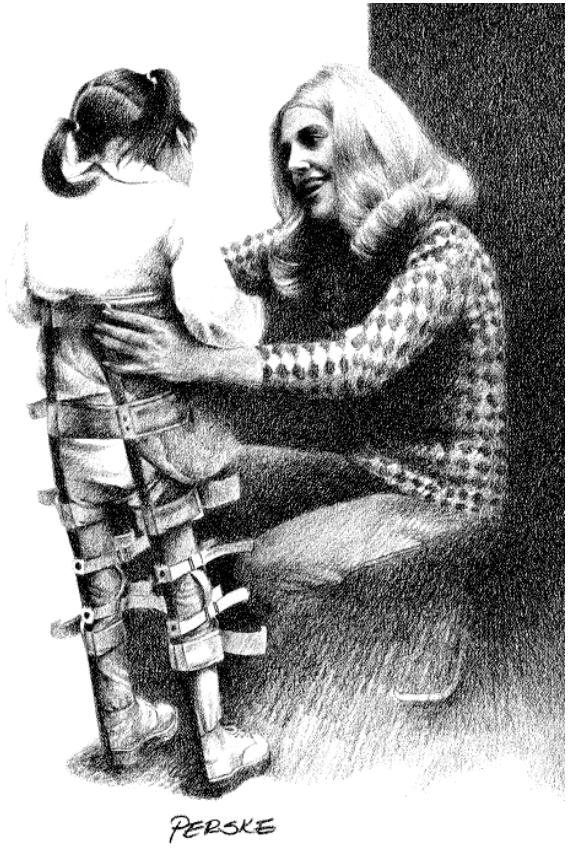
# PEOPLE FIRST LANGUAGE

- **Speak of the PERSON first**
- **Mention the disability ONLY if appropriate**
- **Describe what the person HAS, not IS**
- **LABELS are for JARS**
- **Avoid derogatory terms**

# REASONS FOR INCREASED RISK OF ABUSE AND NEGLECT

## Children with disabilities:

- are easy targets
- are dependent
- can’t (or won’t) tell
- aren’t believed
- seen as “less valuable"

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# SEXUAL ABUSE

## Frequency:

19% One time

17% Two to ten times

64% Repeatedly (over 10 times)

## Locations:

57% Private homes

9% Group homes

8% Public places

4% Rehab centers

10% Vehicles

2% Hospitals

3% Other places

(Mansell, Sobsey and Calder, 1992)

# FAMILY RISK FACTORS FOR ALL CHILDREN

- Violence in the home
- Alcohol and/or substance abuse by parents or caregivers
- Social isolation and lack of external support systems
- Disruption of parental and child attachment
- Presence of high levels of stress in the family, especially financial problems
- Inadequate medical and environmental supports
- Parental expectations inconsistent with the child's developmental abilities
- Adult members of the family have been abused as children

# THE FAMILY SYSTEM:
## Adjustment to Having a Child with A Disability

**Bereavement / Grieving**

**Chronic Sorrow / Disappointment**

**Stages Like . . . .**

Denial

Anger

Depression

Adaptation

Acceptance

**Cyclical versus Sequential**

# FAMILY ADJUSTMENT MILESTONES

Diagnosis

Younger sibling exceeds accomplishments of sibling with disability

Placement

Exacerbated health and/or behavioral problems

Discussion of guardianship and/or extended care

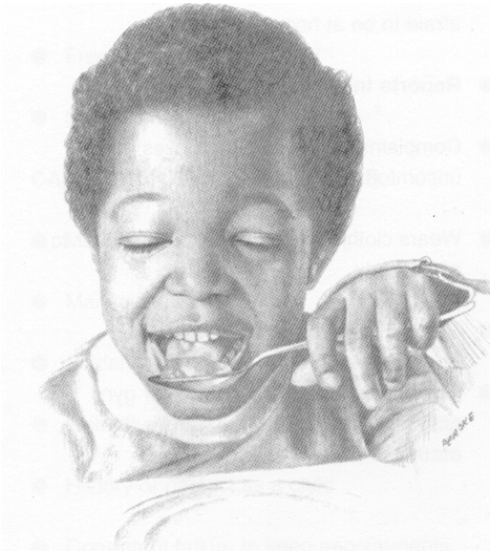
# REALITIES FOR FAMILIES OF CHILDREN WITH DISABILITIES

**30%+ parents reported that child's disability required one or more of these accommodations:**

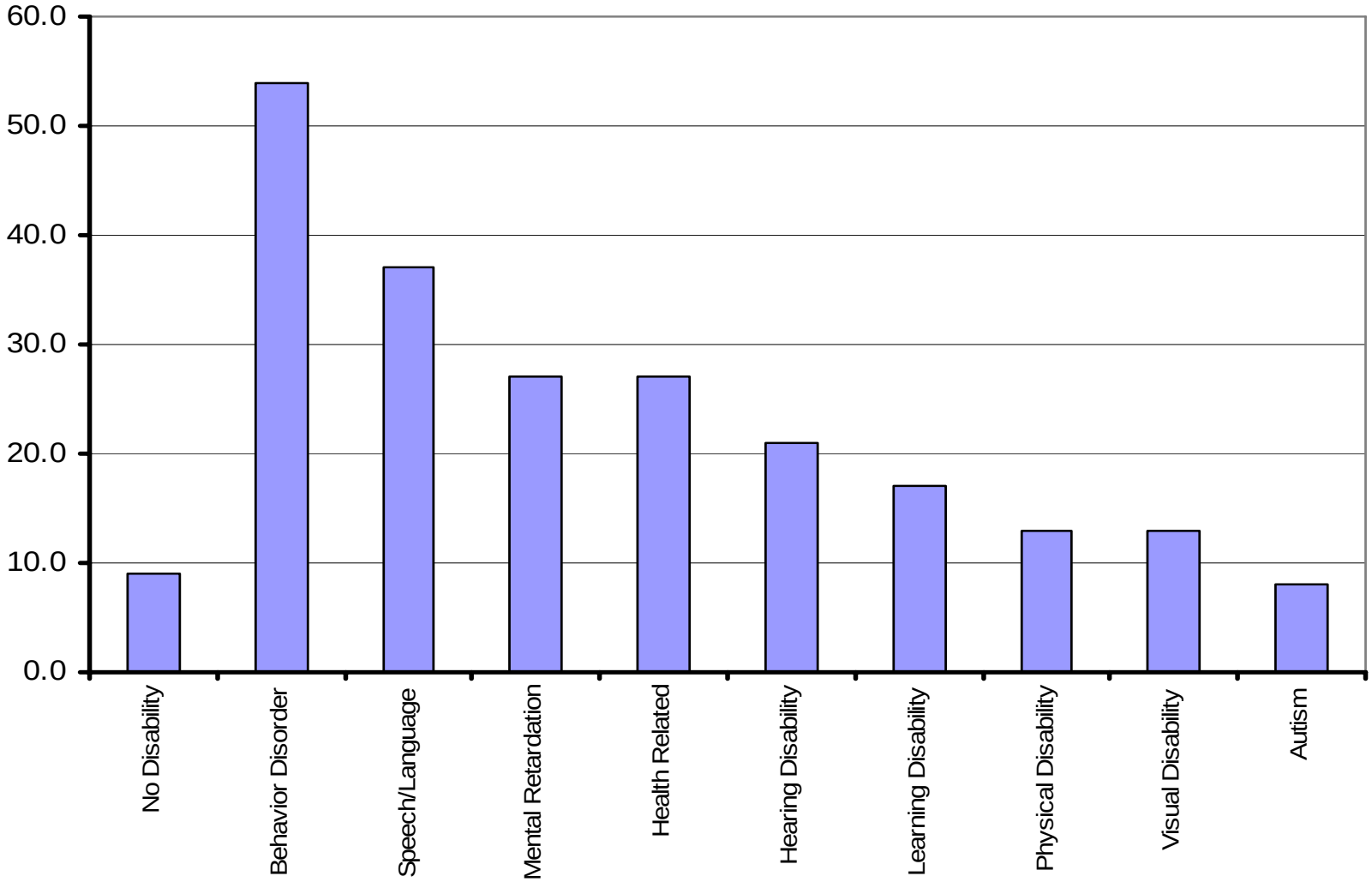
- **Not accepting a job offer**
- **Changing work hours**
- **Working fewer hours**
- **Quitting work**
- **Changing sleep habits**
- **Turning down a better job**
- **Changing jobs**
- **Having financial problems**

# SPECIFIC RISK FACTORS FOR CHILDREN WITH DISABILITIES

- Functional limitations causing lifelong dependency
- Intellectual limitations and mental impairment
- Physical limitations/frailty
- Communication/sensory difficulties
- Naiveté/lack of knowledge



# PREVALENCE OF MALTREATMENT BY DISABILITY STATUS




**Slide B-8**

Sullivan & Knutson 2000, 1262

# CULTURAL MISCONCEPTIONS & STEREOTYPES

- deviant and evil
- contagious
- innocent and pure
- wild
- shameful
- incompetent
- stupid
- without boundaries
- to be feared
- to be pitied or put on a pedestal
- being punished


Baladerian, 1998

# ATTITUDES AND BEHAVIORS

- **Social distancing or depersonalization**
- **Devaluation**
- **Blaming the victim for maltreatment**

(Benedict, Wulff, & White, 1992)

# CHARACTERISTICS OF ABUSIVE INSTITUTIONS

- Extreme power and control inequities
- Isolation
- Dehumanization and detachment
- Clustering
- Abusive subculture
- Covering up abuse


Sobsey, 1994

# COMMUNICATION RISK FACTORS

- Less likely to be able to tell
- Not understood or believed
- Perceived as incompetent
- Perpetrators are aware that victims unable to tell

# FACTORS THAT MAKE IT HARDER TO RECOGNIZE ABUSE AND NEGLECT OF CHILDREN WITH DISABILITIES

- Child does not recognize maltreatment
- Child does not report it
- Greater personal assistance needs
- Fear of not having needs met
- Communication challenges
- Self-abusive behaviors
- Signs of abuse may be interpreted as behavioral problems
- Symptoms may be confused with a disability

Lexington Center, 1994

# REASONS CHILDREN WITH DISABILITIES FAIL TO DISCLOSE MALTREATMENT

- Fear retaliation or loss of care
- Believe they cannot escape or will be in greater danger
- Fear deportation
- Fear repercussions
- Previous attempts to obtain help futile, or resulted in an escalation of violence

# TYPES OF EMOTIONAL ABUSE AND NEGLECT

- **Exposure to domestic violence**
- **Threats**
- **Insults and harassment**
- **Denial of conditions necessary for physical and emotional well-being**
- **Denial of communication**
- **Denial of the right to family life**
- **Denial of social interaction and inclusion**
- **Denial of economic security**
- **Denial of rights, necessities, privileges, and opportunities**
- **Denial of ordinary freedoms**

Roehr Institute, 1995

# CONDITIONS THAT MIMIC SIGNS OF ABUSE

- Injuries due to falls
- Sensory impairments
- Skin breakdown from appliances or orthopedic equipment
- Self-injurious behavior (SIB)
- Poor growth and failure to thrive
- Fractures
- Sensory integration problems
- Mongolian spots

# BEHAVIORS OF ABUSIVE CAREGIVERS

- Authoritarian
- Impulsive
- Hostile towards authority
- Engages in alcohol or drug abuse
- Isolates the person
- Speaks for the person
- Competes with the person
- Blames the person
- Devalues the person
- Cancels medical appointments
- Switches healthcare providers
- Maintains a chaotic home

# FAMILY RESILIENCY AND HEALTHY ADJUSTMENT

- Close family bonds
- Learned patience and compassion
- Family pride
- View their child as a child first
- Not preoccupied with why
- Focus on positive attributes
- Seek and use information
- Cognizant of the educational implications
- Aware of available support groups
- Manage the needs  within context of family
- Father has an active role
- Good communication
- Support from friends and/or relatives
- Opportunities for respite

Virginia Department of Social Services, 2000

# CHARACTERISTICS OF RESILIENT CHILDREN

- Effectiveness in work, play, and love
- Healthy expectancies and a positive outlook
- Self-esteem and internal locus of control
- Self-discipline
- Problem-solving / critical thinking skills
- Humor

# BEHAVIOR AS COMMUNICATION

- All behavior is communication
- Difficult behavior results from unmet needs.
- Needs are always legitimate.

# COMMUNICATION MODEL OF DISABILITY

**INPUT**

Ability to receive information

**PROCESSING**

Understand information and make sense of it

**OUTPUT**

Respond in a way that makes sense

# POSITIVE BEHAVIOR SUPPORT

- Define the behavior
- Collect data
- Determine the function of the behavior
- Develop the Behavioral Intervention Plan
  - Make changes to the environment
  - Teach replacement behaviors
  - Determine reactive strategies
- Collect data
- Review and revise plan

# CRISIS CYCLES

1. Trigger phase
2. Recognizable change in behavior
3. Full-blown crisis
4. Calming down phase
5. Stable calm phase

# POSITIVE STRATEGIES FOR CRISIS MANAGEMENT

- Have a plan
- Refrain from forcing services on the person, except in an emergency
- Know the person's diagnosis
- Insure effective communication
- Keys to success
  - Clear criteria for terminating use
  - Method of record keeping

# RELEASE OF RECORDS TO CPS

***Section 63.2-1509 Code of Virginia*** **authorizes schools to release any records which document the basis for the report.**

# INTERDISCIPLINARY TEAMWORK

- Capitalize on expertise
- Identification of common goals
- Minimize duplication of efforts
- Minimize unnecessary confrontations

**Major investigatory responsibilities include:**

- Determining if maltreatment has occurred
- Protecting the child from further abuse/neglect
- Minimizing trauma to the child as a result of system
- Determining whether a crime has been committed
- Providing or arranging for needed services.

# PRE-INTERVIEW PLANNING

**Important to know:**

- **The child's primary disability**
- **The way the disability impacts upon the child's current functioning**
- **Any accompanying impairments**
- **Communication challenges**
- **Behavior challenges**
- **Distractibility**
- **Where the child receives treatment or special schooling**
- **Special care needed as a result of the disability**

# COMPETENCY ISSUES

**Effective communication is essential for credible evidence.**

**The child's ability to communicate is influenced by:**

- **The interviewer's ability**
- **Child's developmental stage**
- **Child's understanding of the process**

# INTERVIEWING CHILDREN IN SCHOOL

- Private
- Accessible
- Familiar to the child
- Comfortable and suitable for children
- Quiet, with limited noise and distractions
- Close to an accessible restroom
- Frequent breaks may be necessary
- Sit at eye level
- Ask permission to touch assistive devices
- Provide assistance with mobility only when needed and asked